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ABSTRACT

The behavioral and social sciences offer the best perspective on changing individual and group behaviors and stopping the spread of Acquired Immune Deficiency Syndrome (AIDS). Social psychologists interested in basic research and/or theoretical issues have an opportunity to study naturally occurring independent variables. A potential area for basic research is to explore how people weigh the immediate costs of safe behavior against the long-terms benefits of unsafe behaviors in decision-making. Researchers interested in stress research might investigate the relationships between stressors, various mediators, and dependent variables in extreme-stress situations. The potential impact of this tragedy on social and political attitudes should be carefully studied. The impact of the AIDS epidemic on the attitudes and prejudices of people not directly affected can provide the basis for the study of several attributional models. Applied research could undergird the development of prevention programs. For AIDS related programs to be as effective and efficient as possible, researchers should be aware of: (1) the hierarchy of risk; (2) differences in background and experience when selecting target groups; (3) differences in motivation in target groups; (4) development and dissemination of the message; (5) the testing of theory-based approaches; and (6) evaluation. Researchers need to be aware of the best methods for gathering data and federal grant money for funding research. (SM)

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AIDS RESEARCH: AN AGENDA FOR SOCIAL PSYCHOLOGISTS

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AIDS Research: An Agenda for Social Psychologists*

Richard A. Dienstbier

"Without effective treatments or cures, the only hope for stopping the spread of AIDS is through prevention--and the behavioral and social sciences offer the best perspective on changing individual and group behaviors" (Batchelor, 1984).

The Impact of the Epidemic

Since Batchelor issued that call for research in the American Psychologist, the AIDS epidemic has worsened exponentially, as has the need for social research. By current (February, 1988) estimates of the Center for Disease Control (CDC), the United States has had 52,000 AIDS cases, over half of whom have died; it is estimated by CDC that 1.5 million Americans are currently infected with the Human Immunodeficiency Virus (HIV), as indicated by positive blood serum HIV antibody assays. Based on official CDC projections that 20% to 30% of such seropositive individuals will develope AIDS, the CDC projections for 1991 were for 270,000 cumulative U.S. cases of AIDS with 179,000 cumulative deaths.

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While these figures describe a massive epidemic, others estimates suggest even greater devastation. The National Academy of Sciences estimates that 25% to 50% of seropositive individuals will develop AIDS within 5 to 10 years (AIDS Record, 12/15/86). Using studies of deterioration in 543 seropositive individuals whose infection dates could be established, researchers in Frankfurt, Germany have projected that 50% of infected individuals within 5 years and 75% within 7 years will progress to the final stages of AIDS. In keeping with the findings of some researchers of no decline in susceptibility to AIDS with time following infection (Kaplan et al., 1987) the computer model developed by the the Los Alamos National Laboratory, New Mexico ("Massive Toll," 1987) team predicts "virtually all" seropositive individuals will die within 15 years of infection.

Devastation will not be confined to the "risk" groups as currently conceived. Heterosexual transmission of HIV infection from males to females and vice versa is now well established, though the ease of transmission from female to male through coitus is still debated. Where AIDS cases are densely concentrated, the ratio of males to females approaches 1. For example, the 1986 Paris Conference on AIDS estimated that 1% to 2% of the entire African population was seropositive, with most infected individuals concentrated in east and central areas; the male to female ratio of AIDS cases in those areas is thought to be 1. In the U.S., even projecting heterosexual changes toward safer sexual practices beginning in 1987, the Los Alamos computer projections estimate that by the mid 1990's as many heterosexuals as homosexuals will be HIV positive; according to the Los Alamos group, 10% of the American population will be infected by 1994.

Devastation beyond the more obvious loss of health and of life will occur with the continuing epidemic. Based on CDC incidence estimates, the business losses are projected to be $55 billion in 1991 ("The AIDS

Epidemic and Business," 1987). Governments will be affected similarly, since the high incidence of AIDS among intravenous (IV) drug users and the young means that the 35 million Americans without health insurance ("Future Shock," 1986) are over represented in the population of AIDS victims. Not yet integrated into those projections of costs are those associated with infected individuals who develop health problems that are not classified as AIDS (aids related complex -- ARC). Another source of costs apparently not integrated into many of the estimates is that of direct impact on brain functioning of HIV infection (which occurs even in the absence of immune-system manifestations). Some research suggests 1/3 of AIDS patients show some behavioral/mental signs of organic brain damage from action of the virus on neural tissue; at autopsy, 2/3 of AIDS patients show physiological evidence of such damage (Wolcott et al., 1985). Thus the possibility exists that even if a vaccine is developed, it may not cross the blood-brain barrier, so that brain damage from infection may not be prevented.

Even with the development of medical solutions to the medical problems of HIV infection, the impact of this epidemic will be enormous by almost any measure. Without the rapid development of medical solutions, major changes in the fabric of our society will occur.

Basic Research Opportunities

In the context of social ferment, social psychologists interested in basic research and/or theoretical issues will have an opportunity to study inordinantly powerful naturally occuring independent variables. Unfortunately, such basic research, without immediately obvious applications, may appear to be opportunistic in the worst sense. But very basic research often pays off quickly in applications. Basic researchers need not appoligize for trying to extract something of value from disaster. The basic researcher's edge with the AIDS disaster is the predictability that this crisis shall surely grow and become manifest in

locations (and in populations) that are not yet directly affected. The robustness of pre-post designs that also utilize control groups who are not yet experiencing crisis may be frequently possible.

Since basic researchers typically define their own research agendas, I will present only a few ideas here of questions that are of interest to me, and a few examples that might serve as useful models.

Many of the individual decisions for abstinence or safe sex, or to restrict needle sharing, can be conceptualized in terms of immediate costs (of money, convenience, "spontaneity," and even friendship) weighed against long-term benefits (freedom from getting or spreading HIV infection). Whether in real-life contexts or in more controlled simulations, the potential exists for growth in theoretical understanding and growth in knowledge about controlling HIV spread from a study of these complex decisions. Certain personality dimensions will certainly be relevant; sex differences will undoubtedly appear (as in many of the areas suggested in this paper); and decision models, such as that developed by Kahnemen and Tversky (1984) could be both tested and applied.

The extraordinary stressfulness of AIDS provides a basis for stress researchers to test whether relationships between stressors and various mediators and dependent variables may be applicable in such extreme-stress situations. As a model that researchers could build upon, consider the studies by Baum and colleagues (e.g. Baum, 1986) of the long-term impact of the nuclear accident at Three Mile Island. As in that research, in the AIDS crisis careful attention should be paid to mediating variables (such as personality, defensive style, etc.) on a variety of important dependent variables (e.g. mood, mental efficiency, feelings of control, immune system function, illness, psychosomatic complaints, etc.). Considering the confounding of the physiological dependent measures from direct effects of HIV infection, remember that

it is not only the HIV infected who will suffer extreme amounts of stress in the current crisis; lovers, relatives, and friends suffer as well.

A similar example with both basic and applied components is found in Judy Rodin's (1980) research on the impact of fostering feelings of self determination among elderly patients. Neuroendocrine, immune system, longevity, and quality of life dependent measures all reflected a strong positive impact from Rodin's manipulations.

The potential impact of this tragedy on social and political attitudes should be carefully studied. We shall soon become painfully conscious of the suggestions of the Authoritarian Personality researchers that fears and insecurity often lead to extremism and hate, and the building of personal, social, and political fortresses. But those are not inevitable relationships. What mediators in the form of knowledge, attitudes, values, religious beliefs, temperament, defensive and social structures, focus upon victims rather than victimizers, etc. may moderate those relationships? Why are some driven to personal sacrifice for the victims, and others to hate and distance?

As an example of a specific hypothesis derived from headlines about the crisis, I have wondered whether the increased AIDS-related fear and hostility toward male homosexuals is a contributing cause of increases in the anti-black and antisemitic behaviors reported in some sources (Landers, 1986; "Bigotry is unwelcome trend," 1987)? If so, what mediators influence that relationship, and what theoretical constructs will best aid our understanding of those phenomena?

The impact of the AIDS epidemic on the attitudes and prejudices of people not directly affected can provide the basis for the study of several attributional models. For example in some yet to be published research, Bernard Weiner and Raymond Perry (1987) have applied Weiner's attributional model to an understanding of AIDS and other stigmatized

conditions. The research is an example of the multiple benefits that are likely from well-constructed basic research. On the one hand, the use of AIDS as one of the stigmatizing conditions provided additional data for a test of Weiner's underlying attributional model. On the other hand, the Weiner and Perry research provides a useful profile of what attributions and responses are typically made toward AIDS victims, compared with victims of other stigmatizing conditions, and how those attributions and responses change when the HIV is transmitted to the victims by different routes.

Although a sound theoretical base is extremely useful for the generation of new hypotheses and for the potential for application of findings into other realms where some modifications of procedures must be made, it is not essential that a well-articulated theoretical foundation always underlie the research. For example, the work by Kelly et al. (1987) finding that physicians would be less willing to go to a party where an AIDS victim was preparing food, and less willing to allow children to visit the AIDS victim (than a leukemia victim) provides a useful perspective on prejudice in the population on urban physicians.

Applied Research Obligations

Through these dark years of insufficient research funds for the social sciences we have maintained our belief that our government was thereby attenuating our potentially vital assistance with the social issues underlying the major world problems of our times. With the AIDS epidemic we are faced with a compelling opportunity and need to justify our professional self esteem.

"Social scientists have a crucial role...in devising effective means for intervention and prevention of illness. They know how to elicit reliable reports of personal behavior, knowledge, and attitudes; how to reach special cultural groups; how social networks, peer interactions, and voluntary associations function within the general society; how

Illustrative research is offered.

I. The hierarchy of risk. We should learn all that we can about the relative dangers for HIV spread from different sexual and drug practices, so that individuals can focus upon the most problematic behaviors if they are unable or unwilling to adopt a complete package of safe acts. We should remain aware that the same behavior may have different associated risks in different parts of the world.

For example, even when anti-smoking campaigns do not result in individual abstinence, it is posible that brands with less nicotine and tar will be chosen. Similarly, while it has been difficult to end the sharing of needles, some IV drug users have begun to disinfect sharred needles with bleach, and thereby effectively prevent HIV spread ("Bleach cuts IV users' risk," 1987).

With respect to sexual behavior, the San Francisco Men's Health Study group (Winkelstein et al., 1987) found that HIV transmission in gay men is statistically linked to receptive anal penetration, with douching exacerbating that risk; oral genital sex and insertive anal sex did not contribute statistically to infection spread in that population. (This does not mean that those practices are truely safe, but they did not contribute statistically significantly to HIV infection in that study.)

II. Differences in background and experience. A thoughtful selection of target groups must be made, keeping in mind that at this point in the AIDS epidemic any people involved in non-monogamous sexual relationships are at risk, but within that large category some may be more easily influenced and/or particularly likely to practice unsafe sex (e.g. teenage boys and girls). Within a target group, an analysis of those who use relatively safer techniques may provide a key to useful educational strategies.

Teens (homosexual and heterosexual) are an important group to

influence toward safe sexual practices. School-based programs are likely to be effective in reaching large numbers, and can be interactive (and thus be potentially effective) rather than based on media information dissemination models. That 21% of AIDS cases occur among 20- to 29-year-olds suggests that initial exposure came quite early ("Teens need information," 1987).

As a research example, McKusick, Conant & Coates (1985) noted that gay men who restricted sexual contacts were younger, in a stable relationship when they learned about AIDS, and had a visual image of what AIDS deterioration looks like. Coates has noted recently that a feeling of personal efficacy and knowing someone who had died of AIDS similarly influence safer sex ("HIV positives play it safe," 1987). (The importance of the efficacy dimension is similarly underscored by the recent review of factors that contribute to teen contraceptive use by the National Research Council (NRC; 1987). Similarly, in their review of anti-smoking programs, Leventhal and Cleary (1980) emphasized the importance of including messages that enhance a feeling of efficacy when fear approaches are used.)

An intimate level of knowledge about the target group is required for asking appropriate questions (see the procedure of Joseph et al. (1984), discussed in a subsequent section), and for suggesting behavior changes that the target group may consider reasonable. Thus while programs designed to reach IV drug users have been developed, information alone about the connection between shared needles and HIV infection is apparently not enough. It may be that needle use information must consider the special bond between "running partners" in the subculture of relatively impoverished IV drug users.

Researchers must heed Rokeach's (1960) warning that we are particularly prone to categorize together members of different stigmatized subgroups. There is not a single culture of gay men.

Similarly, IV drug users belong to other subcultures and Ethnic groups. Differences between groups in exposure to different types of media, differences in underlying values, languages, literacy levels and economic levels mean that many different appraches and different messages will need to be developed. Programs for IV drug users are also potentially complicated by HIV transmission in that group through both needle sharing and unsafe sex practices.

III. Differences in motivation. Between the target groups of interest, different motivations may underly similar sexual behavior; different information levels, values, and attitudes about sex will also exist. Knowledge of these differences is required to efficiently construct effective and theoretically meaningful educational programs. We should be particularly aware of potential sex differences in these dimensions. Differential exposure to different kinds of media between target populations is also likely and relevant to choice of media for information programs.

For example, many individuals in most of the potential adult target populations know the rudiments of "safe" sex practices. Yet, often that knowledge has not resulted in the adoption of positive behavioral changes, particularly in heterosexuals. A recent Trojan condom company survey of students vacationing in Daytona Beach found that while 50% were using condoms to reduce the risk of sexually transmitted diseases (STD's), 23% indicated no changes at all to protect against STD's ("The year of loving dangerously," 1987). Similarly, while 83% of a sample of women were aware of the usefulness of condoms in preventing STD spread, only 24% of that sample planned to use condoms. Obviously, programs that only reiterated already-known dangers of unsafe sex would not be particularly effective.

The picture of safe sex in the gay male population is less certain. Some studies suggest much progress remains (e.g. a Penn State survey

found 52% of gays "turned off" by condoms and not using them consistently ("The year of loving dangerously," 1987). Other recent studies (e.g. as reported by Robin Fox of the Johns Hopkins group and Thomas Coates of the UCSF group at the Third International Conference on AIDS) have emphasized the major changes toward safer sex that have occurred ("HIV Positives Play it Safe," 1987). Gays in rural areas are less likely to take substantial precautions than are gay men from urban areas.

Understanding the (potentially) multiple determinants of sexual behavior may be crucial. For example, McKusick et al. (1985) noted that styles of sexual interaction may be strongly integrated into the self definitions of some gay men; to effect stable changes toward safer sex practices, similarly integration of those practices into self concepts may be necessary.

To illustrate the principle that different groups may require different information packaging, it has been noted that college students will more readily come to lectures about "human sexuality" than to lectures about AIDS.

IV. Developing and disseminating the message. Because of the differences listed in III, different groups will be influenced by different kinds of information disseminated in different forms of media. Research to determine what information is effective in reducing unsafe sexual practices within groups should then be undertaken. Research to establish the most effective manner of disseminating that information should also be undertaken.

Subjects who have knowledge that they are HIV negative will be inspired toward safe sex by different information and considerations than those who test positive, etc. Similarly, given the change in meaning and function of sexual behavior between a first sexual experience (perhaps as an unmarried teen) and sexuality in a stable

monogamous relationship, different message content will surely be differentially effective. (Refer to the Appendix for a comparable look at different motives related to different subgroups of smokers.)

As programs are constructed, we should take advantage of established research that confronts sufficiently similar behaviors and problems. (I have chosen smoking modification programs and programs directed at teenage pregnancy as prototypical examples; there are many others. My summaries of a smoking review by Leventhal and Cleary (1980) and of the National Research Council's (NRC) recently completed (spring 1987) study of teen pregnancy are included as an appendix to this paper.)

As an example of the usefulness of attention to other research areas, McKusick et al. (1985) noted that Leventhal's and Cleary's (1980) smoking research review provided a theoretical basis and data base for constructing safe-sex information. A combination of fear (some may be necessary) and information about personal control (also necessary, to prevent tuning the message out or retreating into dispair) were integrated into safe-sex communications for gay men.

V. Testing theory-based approaches. As communication programs are developed, they must be tied to established theoretical bases. It is (hopefully) obvious from the forgoing that many different educational programs must be developed. It will be possible to build effective new programs based upon elements of established programs only if those elements are understood at a theoretical level.

This theme of the need for a theoretical understanding of and basis for communications (and dissatisfaction with researchers who lose theoretical consciousness) is repeated both by Leventhal and Cleary in their smoking review, and in the NRC's teen pregnancy report. From the forward by William Morrill to the NRC report: "There seemed to be distressingly little discussion about how various interventions work,

political processes work at the local level; and how to effect attitude change. They have studied risk-seeking and addictive patterns and the basis for cooperative rather than selfish behavior" (Jennes, 1986).

Research on Prevention Programs

It has been noted that as medical cures for AIDS fail to appear, calls toward universal screening, identification, and segregation or quarantine of HIV positive individuals will increase. We know that segregation cannot be achieved, and that either universal or risk group screening will drive into hiding those who would feel threatened. The only available means for reasonable containment of the AIDS epidemic is through prevention of the spread of the HIV by the elimination of high risk behaviors. Social psychologists should become involved in the development of effective behavior change programs, the evaluation of those programs, and, since programs to change sexual behavior (and IV drug use) will be controversial, in public advocacy for useful programs. (My focus will be upon safe sex (rather than IV drug) programs.)

The basic behavioral problem is typically framed in a deceptively simple manner: If all individuals remained monogamously with HIV-negative partners, or used reliable condoms consistently, and avoided sharing needles, HIV spread would end. It will not be so easy. If, as suggested by the Institute of Medicine and the National Academy of Sciences Panel, $1 billion is invested in an AIDS focused safe-sex campaign over the next 5 years, we must insure that it is as effective a campaign as can be devised by current knowledge. The programs that we may help to develop and test are unlikely to be redundant, for despite Surgeon General Koop's recent call for such programs, there are very few programs that have been developed to date ("Teens need information," 1987).

For AIDS-relevant progams that are as effective and efficient as possible, I suggest some attention to the following 6 points.

for whom, under what circumstances, and with what intended and unintended effects. And what were the most promising directions for future policy and program development."

VI. Evaluation. These educational programs must be constantly monitored and evaluated for effectiveness. Effectiveness should be defined in a multitude of ways, but, when possible, should include measures of actual sexual practices. To illustrate this requirement, while evaluations of AIDS-information programs designed specifically for school-aged people have shown positive results in knowledge gained ("Teens need Information," 1987), evaluations of the extensive education program by the British government failed to show concomitant behavioral changes ("Prevention around the world," 1987).

Other behavioral dependent measures should also be considered; for example relevant measures could include condom purchases (or other objective evidence of use), donation of time to condom distribution programs, or donation of time to assisting AIDS patients.

Research on illness and treatment.

A variety of communities, institutions, and individuals who affect and are affected by AIDS victims currently benefit from newly developed educational and training programs. But with the continued expansion of the AIDS epidemic (e.g. virtually every big-city hospital will be treating AIDS victims by 1991) the continued development of programs and the need for evaluation of those programs will expand similarly. While many of the interactions with the victims and the affected people and institutions will be appropriately handled by counselors and clinicians, a role for social psychologists exists in a variety of activities, often by participating in teams with members of other disciplines.

At each of the levels of the outline below, the researcher must be sensitive to potential differences between risk groups, regions of the country, rural versus urban conditions, stages of illness (where

applicable), educational levels, etc.

I. Research on victims. Research is needed to assess beliefs, attitudes, emotional responses, and behavioral dispositions (where appropriate) of individuals who have AIDS, ARC, or HIV-positive status, and the friends, relatives, and lovers of those individuals. Similar research is needed for individuals with fears and concerns relating to risk-group membership, or to living amidst an epidemic.

To date, a significant amount of experience with AIDS victims has led to some understanding of their psychological and social problems. Even the prospect of an HIV seropositive diagnosis is so disturbing that in a recent University of Pittsburgh study, over half of gay and bisexual men who had been given a blood test declined to receive feedback on the nature of that test ("Half of Study Group," 1987). Obviously far more devastating is knowledge of AIDS; patients confront the knowledge of failing health, imminent death, and the potential for loss of mental functioning; they face batteries of unfamiliar medical procedures (Ryan, 1984). The diagnosis often heralds admissions to family, employer, and others of stigmatized behavior or group status (e.g. 4 of 5 gay urban men have not "come out" to their families, according to a survey by Coppola & Zabarsky (discussed by Christ & Wiener, 1985)), and problems develop in areas of professional, financial, social, and sexual functioning. Guilt, fear, anger, and depression are frequently overwhelming. These emotions and doubts may be reinforced by shunning from lovers, friends, family, and even health-care workers, and their stigmatized status is reinforced by the rubber gloves, gowns, and masks that may be worn in the victim's presence (e.g. Geis, Fuller, & Rush, 1986; Coates, Temoshok & Mandel, 1984).

II. Research on helpers. Such research (as suggested in # I) should also focus upon those in professions who impact or are impacted

by people with AIDS or AIDS-related problems.

Health care workers who minister to AIDS victims face a similar array of problems. Most are initially misinformed about the dangers of various forms of transmission of HIV. Besides their own fears and the frequent experience of grief with dying patients, they may be stigmatized by their associaton with AIDS victims and pressured by family and others to discontinue such care. During the earlier years of the epidemic, service delivery was refused by some members of all care groups (Christ & Wiener, 1985). At this point, work role conflicts often develop within staff members who may wish to express their own fears and reservations, but who feel the need to maintain a positive face toward coworkers and supervisors (Geis & Fuller, 1986). New public relations roles may be required of health-care workers as they interact with others from police to laundry workers (Lessor & Jurich, 1986).

III. Research on stress and effectiveness. Analyses are needed of what information and/or interventions will be most useful to reduce the stress experienced and/or increase the effectiveness of the individuals (and institutions) mentioned above in Sections I and II. Such analyses must be followed by research to establish that the information and/or interventions do have the hypothesized positive effects.

It is possible that the coping skills that are effective in improving psychological responses to the HIV infection may similarly relate to the physiological response of the individual to the virus, by modifying immune system processes. Research should focus on those with AIDS, ARC, HIV positive status, and uninfected controls to determine whether and which motivational variables, social adjustment indicators, coping styles, etc. play a role in disease progress.

The responses individuals have to their awareness of different levels of danger interact with their own histories and dispositions (demographic, psychological, social) and the extent and timeliness of

information and counseling already received. For example, there is evidence that those who are denied entrance into the military by virtue of HIV positive blood tests but who are not counseled are unlikely to desist from high risk activities ("AIDS Counseling," undated).

IV. Intervention. Knowing what must be done, the most effectve information and/or intervention programs possible should be developed.

Currently, while we have some knowledge of what coping mechanisms are effective in alleviating stress, we know little about how to encourage the development of effective coping in afflicted individuals (Ryan, 1984).

Various formal and informal interventions have been developed (e.g. the program of informaion and staff discussion at the Sloan-Kettering Cancer Center in New York; Christ & Wiener, 1985). However, once staff fears are reduced there is danger that insufficient care will be taken to eliminate the real danger of infection transmission through infected blood, etc. ("HIV Risk to Health Care," 1987). (E.g.: Although a total of 1500 health care workers have been been found to be HIV negative following needle pricks from needles used in HIV positive individuals, several U.S. cases and a case in Great Britain indicate the possibility of infection from needle pricks and from the splashing of contanimated blood into eyes, mouth, or over chapped or broken skin (Sande, 1986; "A New Worry," 1987).)

The irony of that issue is that while it is apparently difficult to remove the unnecessary rubber gloves from the police and others who have essentially causal contact with AIDS victims, it is not a simple matter to induce proper precautions by those who come into contact with HIV-infected body fluids.

Similar problems will develop in new geographic areas as the epidemic spreads. With the need for new centers to care for the victims, neighbors must be convinced of the acceptability of nearby facilities,

and service personnel from ambulance drivers to funeral directors must become educated to the real dangers and disabused of the unreal dangers of their new roles. Since a major share of programs and research have been developed in San Francisco and New York City, program modifications will probably be needed as similar problems and solutions are imported into other areas.

V. Evaluation. Maintain ongoing evaluations of programs.

Special Research Considerations for AIDS Issues

To reduce invalid answers to questions concerning potentially embarassing, stigmatizing, or illegal activities, a number of excellent techniques are available. Such established techniques are applicable only when researchers' interests are in learning about incidences in a population, rather than in learning about the behavior of a particular individual. Procedures include a randomization device (with known probabilities for various outcomes, such as a coin) combined with the true answer to the question to form the response given. (For example, instructions for the question "are you sexually active" include the instructions to answer "No" only if "No" is the correct answer and a single coin flip (known only to the interviewee) is heads; under all other conditions, answer "Yes." The number of celibate individuals will be double the number of "No's."

Even when respondents intend to give accurate information, McKusick et al. (1985) noted that the recall of sexual behavior is notoriously poor, so that a series of interviews across time of current sexual behavior may be an expensive but optimum strategy.

For asking sensitive questions when individual data is crucial, however, extreme care must be taken. The techniques developed by Joseph et al. (1984) provide a positive model. To insure relevant, unambiguous, and inoffensive language in questionnaires developed for use with gay male populations, Joseph and colleagues, worked with gay community

political and health organizations. They established groups of gay men who discussed such sensitive issues as how the risk of AIDS affected them; such discussions often took several hours. The researchers recorded and then worked from transcripts of those group sessions. They checked back with gay men regarding specific wording and content, and tested the draft questionnaire on a sample of gay men as a further check that the most important issues were being assessed in a sufficiently sensitive manner.

Questionnaires may not always be the best data-gathering method, even when very sensitive issues are at issue. Siegel and Bauman (1986) observed that while some data suggest that more candid responses are obtained on questionnaires, good interview techniques (as developed by the Kinsey group) may be better in the hands of skilled interviewers, provided that there is a match between the interviewer and the client on the topic of interest. Specifically, for sexual topics, a gender match is probably essential. Similarly, for research with gay populations, a sex orientation match is usually recommended. On the other hand, too much rapport may cause bias, so that an interviewer who is somewhat older than the interviewee is preferable in many situations.

Similar concerns underlie the careful interview techniques developed by the the University of San Francisco Biopsychosocial AIDS-Research Project (UCSF-BAP; see Zich & Temoshok, 1986). They noted that if the questions focus exclusively on the very behaviors (needle use, sexual practices) that are properly identified with AIDS, suspicion and rebellion may occur in members of the groups questionned. They caution that interviews with AIDS patients must include some breaks, and that researchers must be aware of the strong possibility of HIV-induced cognitive deficits. They note that AIDS patients will evoke in a sensitive interviewer a desire to provide therapy, but that such responses must be delayed until after the interview. They advise a

technique in which the interviewer's phone number is given, so that if the interview has elicited a need for the patient to talk, the interviewer is available. If particularly emotional material has come out during the interview, the interviewer calls the subject in a day or two to see if there are concerns that need to be discussed.

Due to the extreme stress already experienced by HIV-infected individuals, researchers must be concerned about unnecessary or multiple involvement of an individual in research; the same potential subjects may be asked to participate in a number of different taxing studies. To avoid that problem, the UCSF-BAP researchers (Zich & Temoshok, 1986) formed a clearinghouse to coordinate and standardize psychosocial research efforts in the San Francisco area. They attempted to ensure that the research was congruent with medical research and treatment, and to avoid multiple research participation for AIDS and ARC patients. Regular open meetings to discuss the research were announced in the local gay press. Those who came to the meetings reviewed everything from proposals to confidentiality procedures. In their excellent chapter (recommended reading in the original for potential researchers), Zich and Temoshok emphasize that if there are potential weaknesses in the procedures that insure confidentiality, the intended subject populations will simply not cooperate with the reseachers.

Similarly, those authors suggest that researchers who work directly with AIDS patients or risk groups must be sensitive to all of the potential socio-political ramifications of the procedures and the results of the research, and to be prepared to discuss those possible outcomes with the prospective subjects. Without such sensitivities, the research may never begin.

Zich and Temoshok also emphasize the need for researchers to be careful to control the definition of AIDS, since different physicians apply the CDC standards differently.

Finally, sampling problems are likely; some researchers have suggested that there has never been a representative sample from either of the two (current) major AIDS risk groups.

Federal Grant Funds.

Obviously, the best method of knowing what the federal government wants to fund in the AIDS area is direct contact with the relevant granting agencies. The National Institutes of Mental Health (NIMH) has been interested in funding a wide range of projects on psychiatric, neuropsychological, behavioral, and psychosocial aspects of AIDS, and the role of mood, cognition, and behavioral risk factors. The agency has wanted to fund studies on the relationship of psychological and behavioral variables on immune and endocrine function, and the relationship of those variables to AIDS and ARC. They are interested in the psychological aspects of receiving positive or negative feedback from blood testing for HIV antibodies, influences on and methods of changing high risk sexual behavior, behavioral and psychological characteristics of high risk populations, and evaluation studies of programs to reduce psychiatric or psychological symptoms in AIDS patients.

NIMH is particularly interested in programs and media developed to educate health and mental health workers on medical and psychiatric complications from AIDS, and the psychological, social, and ethical aspects of AIDS and related conditions.

The National Institutes of Drug Abuse (NIDA) emphasis has been on any epidemiological aspects of HIV infection among drug users, routes of transmission from members of those groups to the general population, drug use among prostitutes, interactions between drugs and the immune system, differences in the clinical course for AIDS in people from various populations, and the role of drugs and alcohol as co-factors in the development of AIDS ("Acquired immunodeficiency syndrome," 1986).

Research on Politics, Government, and AIDS.

Marcus Conant noted that we should not assume that AIDS will be the world's last epidemic. It is therefore potentially important to focus upon the reasons that the federal government responded so slowly with concern and funding for public information, research, and patient care. Social psychologists with an interest in public policy and the law may make a particular contribution here. Models for such research already exist; several analyses have been done of media coverage, linking numbers of articles and quality of content to events (particularly the identification of original and subsequent AIDS risk groups) (e.g. Albert, 1986; Baker, 1986).

Another area of interface between the social scientist and government at all levels concerns the funding for the development and institutionalization of school-based sex-education programs. For decades the majority of citizens in most school districts in this country have favored sex education. In part because it is typical for only 10% of citizens to vote in school board elections, it has been possible for a minority opposed to sex education to control school board elections and eliminate sex education, often after good programs had been adopted. While the research on such issues is more in the pervue of political scientists and sociologists than social psychologists, as above, those interested in how such social issues interface with public policy and legal systems may make a significant contribution.

We have another role with respect to the sex education issue as the teachers or potential teachers of college-level human sexuality courses. One of the few (occasionally) legitimate objections to worthwhile school-based sex education is the scarcity of qualified teachers for such curricula. As we anticipate the need for capable sex education teachers, it will be necessary for us to make sure that our human sexuality courses contain material of direct value to such

teachers. A related concern is that the courses be offered at times and seasons so that working teachers can benefit from them.

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Appendix

Two Areas of Research Relevant to Unsafe Sex Prevention: Anti-Smoking Research, as Reviewed by Leventhal and Cleary (1980) and Teenage Pregnancy Issues, as Presented by the National Research Council (1987)

Anti-smoking research

Leventhal and Cleary (1980) reviewed the research and theory of behavioral risk management as applied to smoking. While elements of their review are briefly presented here to illustrate the principle that much can be gained from the study of related areas, serious AIDS program researchers are advised to read the original.

Leventhal and Cleary noted that clinically based interventions (as opposed to public-health based media interventions) tend to be far more effective in the short turn (in stopping smoking) than in the long, emphasizing the need for long-term followup. They suggested the need for some fear content in anti-smoking messages, but argued that in programs combining fear-inspiring elements and messages about personal vulnerability, effectiveness is lost as message recipients lose their feeling of personal control. Similarly, high self esteem seems essential in mediating the effectiveness of high fear messages. Effectiveness is also inhanced when the benefits of positive behavior are emphasized rather than only the danger of the negative. Intelligence interacts with message fear level, with less able students being more affected by higher fear messages, but with smarter students not so affected. Leventhal and Cleary suggested that effective nonsmoking messages should

tie nonsmoking attitudes to the self concept, and they should influence social and group norms rather than only individual attitudes.

Those reviewers noted different stages in smoking behavior (e.g. preparatin for smoking, beginning, addiction, etc.) with different motivations underlying smoking at each stage. Even within stages, different main reasons are given (accurately, as evidenced by some clever research studies) for smoking; these include (at the maintenance level) addiction, taste, tension reduction, etc.

One of their major criticisms of the anti-smoking research literature made by Leventhal and Cleary is that knowledge of the social-psychological factors mediating the successes and failures of programs are typically not analyzed, so that building upon the successes by understanding them at a theoretical level is not possible.

Teen pregnancy issues

The problems of modifying teenage sexual attitudes and behavior to minimize unwanted teen pregnancy and to minimize HIV infection are obviously closely related. A significant similarity between the safe sexual practices relevant to pregnancy and to AIDS is the equal applicability of abstinence.

On the other hand, there are significant differences between safe sex for pregnancy and for AIDS. For teens the contraceptive of choice is the oral birth-control pill, consumed away from the sexual act, whereas condom use must be initiated with sexual contact. Additionally, direct borrowing from this literature to programs oriented toward unsafe sex between members of other groups (e.g. adult gay men) will be less straightforward. Nevertheless, I present this material as a second illustration that some wheels need not be re-invented.

Determinants of effective contraceptive use by girls include being older, belief that it is the girl's responsibility, high self esteem, a sense of internality and competence, support by family for seeking

family planning services, and most importantly, good communication between a girl and her mother (though whether effected through information or motivation is not known). Determinants of effective use by both boys and girls include frequent intercourse with and an emotional relationship with a single partner, frequency of intercourse generally, personal educational aspirations, education level of parents, knowledge about sex and contraception, and acknowledgement that they are sexually active. But impulsivity, risk seeking, and general social irresponsibility are associated with less use. Many teens delay regular contraceptive use until a year after they have become sexually active.

Those preventative strategies incorporated into programs designed to reduce teen pregnancy include giving knowledge and changing attitudes, making contraception readily available, and enhancing life options so that early parenthood may be seen as less desirable.

Relying mainly on research by Kirby (1984; 1985) the NRC concluded that most currently used school-based sex education programs are not sufficiently comprehensive to effectively influence teenage sexual behavior toward non-reproductive sex; similar ineffectiveness is likely in promoting safe sex relevant to AIDS. However, reasonably comprehensive programs of sex education for teens have been shown to increases contraceptive use and decreases fertility in teens who are already sexually active; such programs are not associated with time of first sexual activity.

Model programs are being developed in Seattle and Atlanta. Teen theater projects in which the teens themselves prepare scripts, stage, and act out skits are used in the Tacoma-Pierce County of Washington. These have been presented as 60-second spots for broadcast on rock radio stations. When such media programs are evaluated, it is usual that dependent measures other than fertility, such as hot-line calls, are used. Electronic media programs are typically found to be more effective

than written communications.

The Alan Guttmacher institute estimated that in 1981 57% of at-risk (for pregnancy) teen women received access to information and contraception through family planning services, with 21% from private physicians, and 30% from organizatons such as Planned Parenthood clinics. (Young men seldom visit such facilities.)

For condom distribution programs to be effective, they must be conducted in combination with information campaigns aimed at countering teen beliefs that contraception is the female's responsibility, that obtaining contraception is difficult for teens, and that condoms reduce sexual spontenaity and pleasure. Programs have included encouraging pharmacies to make prominent displays, installing vending machines in convenient locations, etc. By their nature such programs are difficult to evaluate, but at least one has stimulated substantial fertility reductions in the area served.

The NRC report noted that during the past 5 years 43 school-based clinics have been established in junior and senior highs in 24 communities. Evaluations are generally not completed, but a study in St. Paul, noted a birth rate decline from 79/1000 to 26/1000 (but the abortion rate was unknown). One clinic outside (but near) junior and senior high schools that coordinates with the schools was established in an inner-city neighborhood by Johns Hopkins. Evaluations of the "Self Center" (compared to control schools) by Zabin et al. (1986, in the NRC report) indicated reduced teen fertility, delayed first intercourse, greater knowledge, and increasing contraceptive use. (Several recent programs involving peer counseling and parental involvement have not yet been suffienently evaluated.)

The NRC concluded with concerns equally applicable to sex education for contraception or AIDS: Researchers must focus upon what concerned policy makers, program administrators, advocates, parents, and

adolescents need to know, and how such information, if provided, can make a difference. The commissioners suggested further that we know too little at present about how teen sex fits into the social matrix -- the short- and long-term psychological and social effects of adolescent sexual activity on the two sexes, on teens of different ages and stages of development, in different cultural subgroups, etc. They suggested that program evaluation efforts must always be concerned with adding to this informational void by assessing the process (the means or mediators) they affect. While outcome measures of fertility are important, they are not always obtainable, whereas process measures should always be obtained. Evaluation must be built into programs, not added as an after thought, with attempts made to use measures used by other researchers, so that comparisons between programs are possible. Cost/benefit analyses are also very important if the programs are to become broadly institutionalized.